105TH CONGRESS 2D SESSION

S. 2483

To establish programs regarding early detection, diagnosis, and interventions for newborns and infants with hearing loss.

IN THE SENATE OF THE UNITED STATES

September 16, 1998

Ms. Snowe (for herself and Mr. Harkin) introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

A BILL

To establish programs regarding early detection, diagnosis, and interventions for newborns and infants with hearing loss.

- 1 Be it enacted by the Senate and House of Representa-
- 2 tives of the United States of America in Congress assembled,
- 3 SECTION 1. SHORT TITLE.
- 4 This Act may be cited as the "Early Hearing Loss
- 5 Detection, Diagnosis, and Intervention Act of 1998".
- 6 SEC. 2. PURPOSES.
- 7 The purposes of this Act are to clarify the authority
- 8 within the Public Health Service Act to authorize state-
- 9 wide early detection, diagnosis, referral, and intervention

- 1 networks, technical assistance, a national applied research
- 2 program, and interagency and private sector collaboration
- 3 for policy development, in order to assist the States in
- 4 making progress toward the following goals:
- 5 (1) All babies born in hospitals in the United 6 States and its territories should be screened for 7 hearing loss before leaving the hospital (unless the 8 parents of the children object to the screening).
 - (2) Babies who are not born in hospitals should be screened within the first 3 months of life.
 - (3) Diagnostic audiologic testing, if indicated, should be performed in a timely manner to allow appropriate referral for treatment/intervention before the age of 6 months.
 - (4) All universal newborn hearing screening programs should include a component which ensures linkage to diagnosis and the community system of early intervention services.
 - (5) Public policy in early hearing detection, diagnosis, and intervention should be based on applied research and the recognition that infants, toddlers, and children who are deaf or hard-of-hearing have unique language, learning, and communication needs, and should be the result of consultation with pertinent public and private sectors.

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SEC. 3. STATEWIDE EARLY DETECTION, DIAGNOSIS, AND INTERVENTION NETWORKS. Under the existing authority under the Public Health

- 4 Service Act (42 U.S.C. 201 et seq.), the Secretary of
- 5 Health and Human Services (referred to in this Act as
- 6 the "Secretary"), acting through the Administrator of the
- 7 Health Resources and Services Administration, shall make
- 8 awards of grants or cooperative agreements to develop
- 9 statewide early detection, diagnosis, and intervention net-
- 10 works for the following purposes:
- 11 (1) To develop State capacity to support new-12 born hearing loss detection, diagnosis, and interven-
- tion.

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- 14 (2) To monitor the extent to which hearing de-15 tection is conducted in birthing hospitals throughout 16 the State, and assist in the development of universal 17 newborn hearing detection programs in birthing hos-18 pitals and nonhospital birthing sites.
 - (3) To develop statewide models which ensure effective screening, referral, and linkage with appropriate diagnostic, medical, and qualified early intervention services, providers, and programs. Early intervention includes referrals to schools and agencies, including community, consumer and parent-based agencies and organizations and other programs mandated under part C of the Individuals

1	with Disabilities Education Act, which offers pro-
2	grams specifically designed to meet the unique lan-
3	guage and communications needs of deaf and hard
4	of hearing infants, toddlers and children.
5	(4) To collect data on statewide early detection
6	diagnosis, and intervention that can be used for ap-
7	plied research and policy development.
8	SEC. 4. TECHNICAL ASSISTANCE, DATA MANAGEMENT, AND
9	APPLIED RESEARCH.
10	(a) Centers for Disease Control and Preven-
11	TION.—Under the existing authority under the Public
12	Health Service Act (42 U.S.C. 201 et seq.), the Secretary
13	acting through the Director of the Centers for Disease
14	Control and Prevention, shall make awards of grants or
15	cooperative agreements to provide technical assistance to
16	State agencies to complement an intramural program and
17	to conduct applied research related to infant hearing de-
18	tection, diagnosis, and treatment/intervention. The pro-
19	gram shall carry out the following:
20	(1) Provide technical assistance on data collec-
21	tion and management.
22	(2) Develop standardized procedures for data
23	management to ensure quality monitoring of infant
24	hearing loss detection, diagnosis, and intervention

programs.

- 1 (3) Study the costs and effectiveness of hearing 2 detection conducted by State-based programs in 3 order to answer issues of importance to national and 4 State policymakers.
 - (4) Identify the causes and risk factors for congenital hearing loss.
 - (5) Study the effectiveness of early hearing detection, diagnosis, and treatment/intervention programs by assessing the health, developmental, cognitive, and language status of these children at school age.
 - (6) Promote the sharing of data regarding early hearing loss with State-based birth defects and developmental disabilities monitoring programs for the purpose of identifying previously unknown causes of hearing loss.
- 17 (b) National Institutes of Health.—Under the
 18 existing authority under the Public Health Service Act (42
 19 U.S.C. 201 et seq.), the Director of the National Institutes
 20 of Health, acting through the Director of the National In21 stitute on Deafness and Other Communication Disorders,
 22 shall for purposes of this Act continue a program of re23 search on the efficacy of new screening techniques and
 24 technology, including studies of screening methods, studies

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- 1 on efficacy of intervention, and related basic and applied
- 2 research.

3 SEC. 5. COORDINATION AND COLLABORATION.

- 4 (a) In General.—In carrying out programs under
- 5 this Act, under the existing authority under the Public
- 6 Health Service Act (42 U.S.C. 201 et seq.), the Adminis-
- 7 trator of the Health Resources and Services Administra-
- 8 tion, the Director of the Centers for Disease Control and
- 9 Prevention, and the Director of the National Institutes of
- 10 Health shall collaborate and consult with other Federal
- 11 agencies; State and local agencies (including those respon-
- 12 sible for early intervention services pursuant to part C of
- 13 the Individuals with Disabilities Education Act); consumer
- 14 groups serving individuals who are deaf and hard-of-hear-
- 15 ing; persons who are deaf and hard-of-hearing and their
- 16 families; qualified professional personnel who are pro-
- 17 ficient in deaf or hard-of-hearing children's language and
- 18 who possess the specialized knowledge, skills, and at-
- 19 tributes needed to serve deaf and hard-of-hearing infants,
- 20 toddlers, children, and their families; other health and
- 21 education professionals and organizations; third-party
- 22 payers and managed care organizations; and related com-
- 23 mercial industries.
- 24 (b) Policy Development.—Under the existing au-
- 25 thority under the Public Health Service Act (42 U.S.C.

- 1 201 et seq.), the Administrator of the Health Resources
- 2 and Services Administration, the Director of the Centers
- 3 for Disease Control and Prevention, and the Director of
- 4 the National Institutes of Health shall coordinate and col-
- 5 laborate on recommendations for policy development at
- 6 the Federal and State levels and with the private sector,
- 7 including consumer and professional based organizations,
- 8 with respect to early hearing detection, diagnosis, and
- 9 treatment/intervention.
- 10 (c) State Early Detection, Diagnosis, and
- 11 Intervention Networks; Data Collection.—Under
- 12 the existing authority under the Public Health Service Act
- 13 (42 U.S.C. 201 et seq.), the Administrator of the Health
- 14 Resources and Services Administration and the Director
- 15 of the Centers for Disease Control and Prevention shall
- 16 coordinate and collaborate in assisting States to establish
- 17 early detection, diagnosis, and intervention networks
- 18 under section 3 and to develop a data collection system
- 19 under section 4.

20 SEC. 6. RULE OF CONSTRUCTION.

- Nothing in this Act shall be construed to preempt or
- 22 prohibit State laws which do not require the screening for
- 23 hearing loss of newborn infants or young children of par-
- 24 ents who object to the screening on the ground that such

- 1 screening conflicts with the parents' sincerely held reli-
- 2 gious beliefs.

3 SEC. 7. AUTHORIZATION OF APPROPRIATIONS.

- 4 (a) Statewide Early Detection, Diagnosis, and
- 5 Intervention Networks.—For the purpose of carrying
- 6 out section 3, under the existing authority under the Pub-
- 7 lie Health Service Act (42 U.S.C. 201 et seq.), there are
- 8 authorized to be appropriated \$5,000,000 for fiscal year
- 9 1999, \$8,000,000 for fiscal year 2000, and such sums as
- 10 may be necessary for each of the fiscal years 2001 through
- 11 2003.
- 12 (b) Technical Assistance, Data Management,
- 13 AND APPLIED RESEARCH.—
- 14 (1) Centers for disease control and pre-
- 15 VENTION.—For the purpose of carrying out section
- 16 4(a), under the existing authority under the Public
- Health Service Act (42 U.S.C. 201 et seq.), there
- are authorized to be appropriated \$5,000,000 for
- 19 fiscal year 1999, \$7,000,000 for fiscal year 2000,
- and such sums as may be necessary for each of the
- 21 fiscal years 2001 through 2003.
- 22 (2) National institutes of health.—For
- 23 the purpose of carrying out section 4(b), under the
- existing authority under the Public Health Service
- Act (42 U.S.C. 201 et seq.), there are authorized to

- 1 be appropriated \$3,000,000 for fiscal year 1999,
- 2 \$4,000,000 for fiscal year 2000, and such sums as
- may be necessary for each of the fiscal years 2001

4 through 2003.

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